

PUBLIC HEALTH SERVICE ACT

[As Amended Through P.L. 116–324, Enacted January 5, 2021]

[Currency: This publication is a compilation of the text of title XXIX of Chapter 373 of the 78th Congress. It was last amended by the public law listed in the As Amended Through note above and below at the bottom of each page of the pdf version and reflects current law through the date of the enactment of the public law listed at <https://www.govinfo.gov/app/collection/comps/>]

[Note: While this publication does not represent an official version of any Federal statute, substantial efforts have been made to ensure the accuracy of its contents. The official version of Federal law is found in the United States Statutes at Large and in the United States Code. The legal effect to be given to the Statutes at Large and the United States Code is established by statute (1 U.S.C. 112, 204).]

[References in brackets [] are to title 42, United States Code]

TITLE XXIX—LIFESPAN RESPITE CARE

SEC. 2901. [300ii] DEFINITIONS.

In this title:

(1) ADULT WITH A SPECIAL NEED.—The term “adult with a special need” means a person 18 years of age or older who requires care or supervision to—

- (A) meet the person’s basic needs;
- (B) prevent physical self-injury or injury to others; or
- (C) avoid placement in an institutional facility.

(2) AGING AND DISABILITY RESOURCE CENTER.—The term “aging and disability resource center” means an entity administering a program established by the State, as part of the State’s system of long-term care, to provide a coordinated system for providing—

- (A) comprehensive information on available public and private long-term care programs, options, and resources;
- (B) personal counseling to assist individuals in assessing their existing or anticipated long-term care needs, and developing and implementing a plan for long-term care designed to meet their specific needs and circumstances; and
- (C) consumer access to the range of publicly supported long-term care programs for which consumers may be eligible, by serving as a convenient point of entry for such programs.

(3) CHILD WITH A SPECIAL NEED.—The term “child with a special need” means an individual less than 18 years of age who requires care or supervision beyond that required of children generally to—

- (A) meet the child’s basic needs; or
- (B) prevent physical injury, self-injury, or injury to others.

(4) **ELIGIBLE STATE AGENCY.**—The term “eligible State agency” means a State agency that—

(A) administers the State’s program under the Older Americans Act of 1965, administers the State’s program under title XIX of the Social Security Act, or is designated by the Governor of such State to administer the State’s programs under this title;

(B) is an aging and disability resource center;

(C) works in collaboration with a public or private nonprofit statewide respite care coalition or organization; and

(D) demonstrates—

(i) an ability to work with other State and community-based agencies;

(ii) an understanding of respite care and family caregiver issues across all age groups, disabilities, and chronic conditions; and

(iii) the capacity to ensure meaningful involvement of family members, family caregivers, and care recipients.

(5) **FAMILY CAREGIVER.**—The term “family caregiver” means an unpaid family member, a foster parent, or another unpaid adult, who provides in-home monitoring, management, supervision, or treatment of a child or adult with a special need.

(6) **LIFESPAN RESPITE CARE.**—The term “lifespan respite care” means a coordinated system of accessible, community-based respite care services for family caregivers of children or adults with special needs.

(7) **RESPITE CARE.**—The term “respite care” means planned or emergency care provided to a child or adult with a special need in order to provide temporary relief to the family caregiver of that child or adult.

(8) **STATE.**—The term “State” means any of the several States, the District of Columbia, the Virgin Islands of the United States, the Commonwealth of Puerto Rico, Guam, American Samoa, and the Commonwealth of the Northern Mariana Islands.

SEC. 2902. [300ii-1] LIFESPAN RESPITE CARE GRANTS AND COOPERATIVE AGREEMENTS.

(a) **PURPOSES.**—The purposes of this section are—

(1) to expand and enhance respite care services to family caregivers;

(2) to improve the statewide dissemination and coordination of respite care; and

(3) to provide, supplement, or improve access and quality of respite care services to family caregivers, thereby reducing family caregiver strain.

(b) **AUTHORIZATION.**—Subject to subsection (e), the Secretary is authorized to award grants or cooperative agreements for the purposes described in subsection (a) to eligible State agencies for which an application is submitted pursuant to subsection (d).

(c) **FEDERAL LIFESPAN APPROACH.**—In carrying out this section, the Secretary shall work in cooperation with the National Family

Caregiver Support Program of the Administration on Aging and other respite care programs within the Department of Health and Human Services to ensure coordination of respite care services for family caregivers of children and adults with special needs.

(d) APPLICATION.—

(1) SUBMISSION.—Each Governor desiring the eligible State agency of his or her State to receive a grant or cooperative agreement under this section shall submit an application on behalf of such agency to the Secretary at such time, in such manner, and containing such information as the Secretary shall require.

(2) CONTENTS.—Each application submitted under this section shall include—

(A) a description of the eligible State agency's—

(i) ability to work with other State and community-based agencies;

(ii) understanding of respite care and family caregiver issues across all age groups, disabilities, and chronic conditions; and

(iii) capacity to ensure meaningful involvement of family members, family caregivers, and care recipients;

(B) with respect to the population of family caregivers to whom respite care information or services will be provided or for whom respite care workers and volunteers will be recruited and trained, a description of—

(i) the population of family caregivers;

(ii) the extent and nature of the respite care needs of that population;

(iii) existing respite care services for that population, including numbers of family caregivers being served and extent of unmet need;

(iv) existing methods or systems to coordinate respite care information and services to the population at the State and local level and extent of unmet need;

(v) how respite care information dissemination and coordination, respite care services, respite care worker and volunteer recruitment and training programs, or training programs for family caregivers that assist such family caregivers in making informed decisions about respite care services will be provided using grant or cooperative agreement funds;

(vi) a plan for administration, collaboration, and coordination of the proposed respite care activities with other related services or programs offered by public or private, nonprofit entities, including area agencies on aging;

(vii) how the population, including family caregivers, care recipients, and relevant public or private agencies, will participate in the planning and implementation of the proposed respite care activities;

(viii) how the proposed respite care activities will make use, to the maximum extent feasible, of other Federal, State, and local funds, programs, contribu-

tions, other forms of reimbursements, personnel, and facilities;

(ix) respite care services available to family caregivers in the eligible State agency's State or locality, including unmet needs and how the eligible State agency's plan for use of funds will improve the coordination and distribution of respite care services for family caregivers of children and adults with special needs;

(x) the criteria used to identify family caregivers eligible for respite care services;

(xi) how the quality and safety of any respite care services provided will be monitored, including methods to ensure that respite care workers and volunteers are appropriately screened and possess the necessary skills to care for the needs of the care recipient in the absence of the family caregiver; and

(xii) the results expected from proposed respite care activities and the procedures to be used for evaluating those results;

(C) assurances that, where appropriate, the eligible State agency will have a system for maintaining the confidentiality of care recipient and family caregiver records; and

(D) a memorandum of agreement regarding the joint responsibility for the eligible State agency's lifespan respite program between—

(i) the eligible State agency; and

(ii) a public or private nonprofit statewide respite coalition or organization.

(e) PRIORITY; CONSIDERATIONS.—When awarding grants or cooperative agreements under this section, the Secretary shall—

(1) give priority to eligible State agencies that the Secretary determines show the greatest likelihood of implementing or enhancing lifespan respite care statewide; and

(2) give consideration to eligible State agencies that are building or enhancing the capacity of their long-term care systems to respond to the comprehensive needs, including respite care needs, of their residents.

(f) USE OF GRANT OR COOPERATIVE AGREEMENT FUNDS.—

(1) IN GENERAL.—

(A) REQUIRED USES OF FUNDS.—Each eligible State agency awarded a grant or cooperative agreement under this section shall use all or part of the funds—

(i) to develop or enhance lifespan respite care at the State and local levels;

(ii) to provide respite care services for family caregivers caring for children or adults;

(iii) to train and recruit respite care workers and volunteers;

(iv) to provide information to caregivers about available respite and support services; and

(v) to assist caregivers in gaining access to such services.

(B) **OPTIONAL USES OF FUNDS.**—Each eligible State agency awarded a grant or cooperative agreement under this section may use part of the funds for—

- (i) training programs for family caregivers to assist such family caregivers in making informed decisions about respite care services;
- (ii) other services essential to the provision of respite care as the Secretary may specify; or
- (iii) training and education for new caregivers.

(2) **SUBCONTRACTS.**—Each eligible State agency awarded a grant or cooperative agreement under this section may carry out the activities described in paragraph (1) directly or by grant to, or contract with, public or private entities.

(3) **MATCHING FUNDS.**—

(A) **IN GENERAL.**—With respect to the costs of the activities to be carried out under paragraph (1), a condition for the receipt of a grant or cooperative agreement under this section is that the eligible State agency agrees to make available (directly or through donations from public or private entities) non-Federal contributions toward such costs in an amount that is not less than 25 percent of such costs.

(B) **DETERMINATION OF AMOUNT CONTRIBUTED.**—Non-Federal contributions required by subparagraph (A) may be in cash or in kind, fairly evaluated, including plant, equipment, or services. Amounts provided by the Federal Government, or services assisted or subsidized to any significant extent by the Federal Government, may not be included in determining the amount of such non-Federal contributions.

(g) **TERM OF GRANTS OR COOPERATIVE AGREEMENTS.**—

(1) **IN GENERAL.**—The Secretary shall award grants or cooperative agreements under this section for terms that do not exceed 5 years.

(2) **RENEWAL.**—The Secretary may renew a grant or cooperative agreement under this section at the end of the term of the grant or cooperative agreement determined under paragraph (1).

(h) **MAINTENANCE OF EFFORT.**—Funds made available under this section shall be used to supplement and not supplant other Federal, State, and local funds available for respite care services.

SEC. 2903. [300ii-2] NATIONAL LIFESPAN RESPITE RESOURCE CENTER.

(a) **ESTABLISHMENT.**—The Secretary may award a grant or cooperative agreement to a public or private nonprofit entity to establish a National Resource Center on Lifespan Respite Care (referred to in this section as the “center”).

(b) **PURPOSES OF THE CENTER.**—The center shall—

- (1) maintain a national database on lifespan respite care;
- (2) provide training and technical assistance to State, community, and nonprofit respite care programs; and
- (3) provide information, referral, and educational programs to the public on lifespan respite care.

SEC. 2904. [300ii-3] DATA COLLECTION AND REPORTING.

(a) **IN GENERAL.**—Each State agency awarded a grant or cooperative agreement under section 2902 shall report such data, information, and metrics as the Secretary may require for purposes of—

(1) evaluating State programs and activities funded pursuant to such grant or cooperative agreement, including any results pursuant to section 2902(d)(2)(B)(xii); and

(2) identifying effective programs and activities funded pursuant to section 2902.

(b) **REPORT.**—Not later than October 1, 2023, the Secretary shall submit a report to the Committee on Health, Education, Labor, and Pensions of the Senate and the Committee on Energy and Commerce of the House of Representatives regarding the outcomes of the programs and activities funded pursuant to section 2902, including any effective programs and activities identified.

SEC. 2905. [300ii-4] AUTHORIZATION OF APPROPRIATIONS.

There are authorized to be appropriated to carry out this title, \$10,000,000 for each of fiscal years 2020 through fiscal year 2024.